DOCUMENT RESUME

ED 242 174 EC 162 145

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TITLE Peer Support as a Mediator in Stress Reduction for Parents of Children with Disabilities.
PUB DATE Apr 83
NOTE 14p.; Paper presented at the Annual Montana Symposium on Early Education and the Exceptional Child (4th, billings, MT, April 27-29, 1983); see EC 162 142.
PUB TYPE Speeches/Conference Papers (150) -- Guides - Non-Classroom Use (055)

EDRS PRICE MF01/PC01 Plus Postage.
DESCRIPTORS *Disabilities; *Parent Associations; Parent Education; Parents; *Peer Counseling; *Peer Groups

ABSTRACT

Peer support can be helpful in reducing the stress involved in giving birth to and raising a child with handicaps. A peer support group can help meet the parents' needs for information, emotional support, and ways to connect with social/health systems components. To be successful, a peer support system should be led by parents, have access to professional support, teach special skills such as active listening, be sanctioned by the medical community, have a paid staff, and operate under an umbrella agency. (CL)

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Peer Support as a Mediator in Stress Reduction for Parents of Children with Disabilities

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EC 162145

Paper presented at the Fourth Annual Montana Symposium on Early Education and the Exceptional Child, Billings, Montana, April 27-29, 1983

Unquestionably, the birth of a child with a disability is a cause for stress among family members. Simply having a child produces some stress for parents (McGuive and Gottlieb, 1979; Wandersman, Wandersman, and Kuhn, 1980); if the child has a handicap, the stress increases (Birenbaum, 1971; Friedrich and Friedrich, 1981; Hannon, 1974; Holroyd and Guthrie, 1979; Holroyd and McArthur, 1976; Howard, 1978; Olshensky, 1962) for the parents and other family members who were expecting the arrival of a healthy baby. The shock of a "not perfect baby" is devastating. The gradual suspicion that"something is wrong" (as in the case of the first few monthsof life with a child with cerebral palsy) can also lead to tension, depression and the general responses to depression and stress.

Although the stages may vary, the Family's acceptance of a child with a disability follows a somewhat predictable course. There is shock and disbelief, followed by an overwhelming desire to "know why" (Hannon, 1974). "Why did this happen?" "Am I to blame?" Who is to blame?" What is to blame?" How did this happen?" This phase of often followed by anger, especially when there are no clear cut answers to the previous questions (as in the great majority of the cases). Discomfort follows, often caused by the social pressures of the situation. "What will I tell my mother-in-law?" "How do we interact with the neighbors?" "What will the older child tell his playmates?" Uncertainty due to the demands of the child disability often adds both physical and emotional stress. A child who is difficult to feed increases a mother's fatigue. Medically fragile children are a

constant source of anxiety for the parents, and keep them in a state of uncertainty - about the life of the child and about their own adequacies. Frustration, follows. The pressures mount with the need to locate medical, educational, and therapeutic services for the child; to interact with a variety of professionals, and to deal with the financial strain of acquiring these services. The journey is a long one before the family resolves the issues involved in caring for a child with a disability.

Too much stress impairs function. While the exact amount of stress which is "too much" may be variable for different family units, there can be little doubt that the introduction of a child with a disability into a family is "too much stress," at least at first. The feelings of grief, sadness, anger, frustration, helplessness, and often incompetence lead to a sense of lack of self-worth. Interpersonal relations among family members often deteriorate. Relatives, friends and neighbors often simply do not know how to respond to the situation and withdraw. The family isolates itself from its support system. Daily routines suffer, as family members who can escape usually do so. Often the father spends more time at work, and older children more time in school, leaving the mother in still greater isolation. Individual reactions to the grief and anger may be misunderstood by others in the family as placing blame. The vicious cycle of negative interactions feeds on itself.

How any single family unit responds to stress produced by a child with a disability will vary greatly according to the individuals, the educational levels, the religious beliefs, past experiences with dis-

ability, ethnic background, socio-economic status, and total family make-up. All families, however, will experience increased stress. The issue, then, becomes how to best reduce (mediate) the stress.

There appear to be four (4) major types of support that can serve to alleviate the negative aspects of stress in families: 1) the presence of a significant other; 2) peer support; 3) timely and accurate information; 4) specific skills related to immediate issues. The research literature clearly indicates that the presence of another individual who unconditionally loves the person under stress (significant other) serves to significantly decrease the negative effects of stress. Outside intervention that provides people with "significant others" is usually (understandably) not a major function of social service systems. Peers (in this case other families with handicapped children) provide family members with realistic empathy, an extremely important ingredient in reducing stress (McGuire and Gottlieb, 1979; Wandersman, Wandersman, and Kuhn, 1980). Peers may also be the sources of information. Timely and accurate information can be used by the families to acquire services, adjust to social situations, respond to specific child needs, and plan for potentially troublesome future events. The emphasis must be on timeliness (information when there is a perceived need by the family) and accuracy. When supplied by peers the information is often viewed as more believable than when supplied by another source. Finally, the most crucial skills are those for managing specific child behaviors that are of immediate concern to the family, and those required to adequately interact with the untold

numbers of professionals in the maze of social services in which parents will find themselves.

The remainder of this manuscript will focus on the role of peer support in mediating stress for families of children with disabilities.

Peer support has been discussed in detail by a number of authors (Caplan, 1974; McGuire and Gottlieb, 1979; Stanifer, 1964; Wandesman, Wandesman, and Kuhn, 1980). Social support (the broader concept under which peer support falls) is defined as a condition in which an individual believes he or she is cared for, held in positive regard by others, and is part of a network of like individuals. There is also the need to explore socially accepted norms around a common event, provide skills and information, share common experiences and feelings, and develop a feeling of "we'ness." Peers, individuals with a common experience, come together at a deep emotional level if the focus is confined to this common experience. Thus, individuals who are <u>not peers</u> according to many variables can relate on the one specific issue which has defined them as peers. Contact with similar others (McGuire and Gottlieb, 1979) allows for the exploration of social comparison through the sharing of common experiences, feelings, and information.

Families during the transition into parenthood tend to lose contact with their social support system. When the new child is handicapped the social isolation often increases. The need for peer support dramatically increases at the exact time when isolation from social contacts occurs. Parents of young handicapped children <u>seldom</u> come together without assistance from an outside agent. Thus, even

though peer support is a (if not the) crucial service for parents of young handicapped children, special procedures must be developed to facilitate the "coming together" of parents.

Needs met by peer support groups. The activities of a parent to parent support group for parents of young handicapped children must be directly related to the needs of the parents: information, emotional support, connections with system components.

There are at least three classes of information often requested by parents of young handicapped children who ask the following questions: what is the nature of the disability and what does this mean for the future of my child? How do I (we) respond to others in informing them about my child's handicap? What should I do next? These questions are persistent and enduring regardless of the answers given at any one time. Thus, even if medical personnel provide extensive information to the parents at the initial informing session and even if adequate written materials are made available, the parents will continue to have questions about the nature, cause, and outcomes of the disability. This is only natural as time is required to develop questions, and to assimilate answers; as noted by Hannon (1974), it doesn't matter what parents are told, what they hear is what matters. Ongoing contact with another parent of a handicapped child offers the new parent opportunity, over time, to think about questions, ask them and listen. Additionally, the answers from a peer tend to be believable.

New parents face a social situation which is very difficult to understand unless they experienced a similar event; how do you inform relatives, friends, and neighbors about your child's disability?

Many professionals (myself included) do not feel comfortable in advising people on this. Having the opportunity to discuss this situation with another person who has been through it before can greatly reduce the stress and anxiety of the task of telling mother-in-laws, work colleagues, and neighbors about the child.

How to access "the system", where to go for services, who are sympathetic professionals, what to expect from a teacher or a physician or a physical therapist, how to fill out forms --- these are questions that cannot be answered at one time. They produce stress unless there is a method to get them answered (or at least someone to listen). No one (or even two or three) professionals can fill this role. What is needed is an empathetic, available "ear" who has information to share --- a peer.

Emotional support. Empathy, the projection of one's consciousness into another being (Webster's New Collegiate Dictionary), is based upon the awareness of having undergone similar experiences. I truly believe that I cannot empathize, totally, with a parent of a child with a disability. I am a parent but my children are not disabled. I have talked to many parents of children with disabilities, I have read and thought about the issues, but I have not felt the feelings. Real emotional support comes from empathetic peers ---people "with nowhere to hide, you look in their eyes and find yourself" Willie Nelson, Red Headed Stranger"). Peers are able to allow one to cry, to say awful things, to be out of control --- because they have been there. The message that passes between two individuals who share a common experience is a private message outsiders cannot understand. To have a peer

available is to have emotional support.

Connection with system components. Hooking into the system is a complex process. Information must be made available in a timely manner (what services are needed, what programs are available, how to "get into" programs). However, the parents often need a "guide" to assist them in the routines if necessary to efficiently locate and enter programs. Professionals, with turf issues and their own ideas as to what is needed and what is best, are seldom the appropriate persons to assist parents in locating all the needed programs. Peers, parents who have recently been through the identical process, are the logical guides.

Recommended Components of a Peer Support System

Peer support systems do not just occur; they need to be planned, supported by a formal agency, and maintained over time. There are several components that were important in developing and maintaining the King County Advocates for Retarded Citizens Parent to Parent Support Program which I will summarize here (see reference note for King County ARC contact).

Parent leadership. The leadership in the program is best facilitated by parents. Professionals have roles (see next section) but parents need to have the leadership. A peer support program needs a peer as the leader. A small group of parents who have the skills, time and energy to serve as an advisory board is absolutely crucial.

Professional support. Professionals are important as ongoing consultants to the program. The role of the professional is to consult

(when asked), recommend, and provide information. Decisions, however, must be left to the parent advisory board.

Parent education. Special skills are required to be a supportive peer (a helping parent). Most important are the skills associated in listening without "telling" reflection or active listening. Information referral and crisis referral are also important. Part of parent education for the helping parents consists of ongoing peer support from other helping parents - parents getting together and reflecting on their own experiences.

Medical community sanction. Most referrals of new parents to the program probably originate in the medical community. Therefore, the sanction of the peer support program by the medical community is essential. A medical advisory board is a possible strategy for meeting this concern.

Paid staff. Peer support programs that endure are dependent on paid staff. If at all possible the paid staff should be parents. There certainly is ample room for volunteers, but peer support is so important that society needs to value the activity by paying the staff.

Mother agency. A peer support program needs an umbrella agency to host the program. This agency provides space, backup support, and a focal point for outside support. Although any community agency may serve this role, a logical agency is an Association for Retarded Citizens or other parent support organization.

In conclusion, peer support is absolutely crucial for families with disabled children. Peers, other parents of handicapped children, can best supply new parents with information and assistance. More important, peers provide empathy. All of these are important stress mediators.

Reference Notes

1. Helen Pym, Coordinator, King County Advocates for Retarded Citizens Parent to Parent Support Program, King County ARC, Seattle, Washington, (206) 622-9242.

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